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Perrin-Decade Study Grp

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Long-term course of difficulty in participation of individuals with cerebral palsy aged 16 to 34 years: a prospective cohort study

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ABBREVIATIONS

ICF	International Classification of Functioning, Disability and Health
LIFE-H	Assessment of Life Habits questionnaire 3.0 general short form
PERRIN	Pediatric Rehabilitation Research in the Netherlands

AIM To determine the long-term course of difficulty in participation of individuals with cerebral palsy (CP) without intellectual disability between 16 years and 34 years of age.

METHOD One hundred and fifty-one individuals with CP aged 16 to 20 years were included (63% male, 37% female; Gross Motor Function Classification System [GMFCS] levels I–IV; without intellectual disability). The Assessment of Life Habits questionnaire 3.0 general short form was used up to three times biennially and at 13-year follow-up (13-year follow-up: $n=98$). Scores (range 0–10) reflect difficulty and assistance in participation in housing, education and employment, interpersonal relationships, recreation, community life, and responsibilities. Multilevel models were used to determine the course of difficulty in participation by GMFCS level.

RESULTS Despite high average participation levels, 41% to 95% of adolescents and young adults with CP experienced difficulty. Difficulty in participation in housing and interpersonal relationships increased from age 16 years onwards and in most other life areas in the mid- and late 20s. In adolescents in GMFCS levels III and IV, participation in recreation and community life improved up to age 23 years.

INTERPRETATION Individuals with CP experience increasing difficulties in participation in their mid- and late 20s. Clinicians should systematically check for participation difficulties in young adults with CP and offer timely personalized treatment.

Cerebral palsy (CP) is a common childhood-onset physical disability causing activity limitation.¹ CP research and health care have traditionally focused on children, but as these children grow older, their participation in daily life changes. The transition from adolescence to adulthood is considered to be a critical phase to develop optimal participation in society.² Although health care services and education for children with CP are well developed, health care providers often struggle to offer appropriate care to support participation of this group in adulthood.³

Participation is defined by the International Classification of Functioning, Disability and Health (ICF) as ‘involvement in a life situation’ and encompasses, among others, the domains: domestic life, education and employment, interpersonal interactions and relationships, and community, social, and civic life.⁴ Studies on adolescents and adults with CP have demonstrated participation restrictions, that is problems individuals experience in involvement in life situations.^{2,4–12} Some of these studies have addressed whether or not individuals actually performed certain life habits,^{9–11} or how often they performed

them in daily life.^{7,12} According to the ICF, participation performance can be qualified objectively by the experienced difficulty or the use of assistive devices or human assistance needed in performing life habits.⁴ These qualifiers were used in cross-sectional studies showing that adolescents and young adults with CP may experience difficulty in participation, particularly in participation in education and employment and in community, social, and civic life.^{6,8,13,14} One study indicated that low proportions of adults with CP were dependent on human assistance in these participation domains.¹⁴

Although individuals with CP experience difficulty in participation during transition into adulthood,² no systematic knowledge is available on the long-term course of participation towards their late 20s or early 30s. At this age social roles are likely to change, from being dependent on one’s parents to, for instance, living independently, being employed, and maintaining a stable relationship. These changes with increasing age are accompanied by growing social and environmental demands.¹⁵ We therefore hypothesize that difficulty in participation increases for individuals

with CP in their mid- or late 20s. The aim of the present study was to longitudinally investigate difficulty in participation in this age range by Gross Motor Function Classification System (GMFCS) level, since level of function is known to be related to participation.^{9,13,16} Furthermore, in the present study we focus on individuals *without* intellectual disability, since participation trajectories differ greatly for individuals with intellectual disability.⁹ These longitudinal curves may help individuals with CP and health care providers to timely focus on those aspects of participation where difficulties are experienced, in order to achieve optimal participation in adult life. Therefore, this study examines the long-term course of difficulty in participation of individuals with CP in GMFCS levels I to IV (without intellectual disability) aged 16 to 34 years.

METHOD

Participants

The long-term prospective cohort study PERRIN DECADE is part of the Pediatric Rehabilitation Research in the Netherlands (PERRIN) programme. A 13-year follow-up assessment was performed of the PERRIN 9 to 16 cohort (baseline age: 9–13y, $n=108$), with previous yearly assessments over the course of 3 years; and the PERRIN 16 to 24 cohort (baseline age: 16–20y, $n=103$), with three previous biennial assessments over the course of 4 years. The recruitment process for both cohorts is described elsewhere.^{13,17} Eligible participants had a clinical diagnosis of CP and sufficient knowledge of the Dutch language to participate. In the PERRIN 16 to 24 cohort study, individuals with intellectual disability (roughly $IQ < 70$) were excluded, since its primary focus was transition to an independent adult lifestyle.¹³

PERRIN-DECADE recruitment

The study was approved by the medical ethical committees of VU University Medical Center and Erasmus MC University Medical Center. Figure S1 (online supporting information) presents a flowchart of the 13-year follow-up recruitment and observations included in the present study. Of all 211 participants of the PERRIN 9 to 16 and PERRIN 16 to 24 cohorts, 198 participants were invited for a 13-year follow-up assessment. The remaining 13 former participants were not invited because (1) one had deceased, (2) nine had indicated no interest in further participation, and (3) three were excluded (their initial diagnosis could not be confirmed). Finally, 122 participants (62% response) gave informed consent and participated in the 13-year follow-up assessment. The follow-up data were added to the existing longitudinal PERRIN database, which was used for the present analyses.

The present study addresses difficulty in participation, for which data were collected only for individuals aged 16 years or over; thus, individuals without observations over age 16 years were excluded ($n=33$). In addition, individuals with intellectual disability ($n=21$) or in GMFCS

What this paper adds

- Many individuals with cerebral palsy (CP) aged 16 to 34 years experience difficulty in participation.
- Difficulty in participation increases in the mid- and late 20s for individuals with CP.
- Participation in recreation/community life improves before age 23 years for those in Gross Motor Function Classification System levels III and IV.

level V ($n=3$) were excluded because of the small numbers of individuals in these categories with longitudinal observations. Thus, 151 individuals with CP (without intellectual disability) were included in the present analyses; of these, 105 (70%) were measured twice or more (see Figure S2, online supporting information).

Measures

Life Habits questionnaire

To assess difficulty in participation, an aspect of restricted participation, the Dutch version of the Assessment of Life Habits questionnaire 3.0 general short form (LIFE-H) was administered. In addition to the domains addressing social roles (interpersonal relationships, education, employment, recreation, community life, and responsibilities), the housing domain was also assessed as we considered this to reflect a relevant domain of participation.^{4,18} All domains contain six to eight items, except for the education domain (three items). The employment and education domains were combined into one score, since only one item of the education domain (either participation in high school or professional training) was applicable for each participant, and the employment domain includes two items that can reflect participation in education.

Items addressed two ICF qualifiers of participation performance: the difficulty experienced and the assistance needed with a life habit. Difficulty was recorded as 'no difficulty', 'some difficulty', 'accomplished by a proxy', or 'not accomplished'. Assistance was recorded as 'no assistance', 'use of assistive device', 'adaptation', and/or 'with human assistance' (dependent functioning). If an item was applicable, a combined item score of 0 to 9 was assigned.¹⁹ From item scores mean domain scores were calculated, which were linearly transformed into a 0 to 10 score, with 10 indicating optimal participation (see Table SI, online supporting information). Principal component analysis has shown acceptable unidimensionality within each domain,²⁰ thus supporting their use as an interval scale. LIFE-H domain scores of 8.89 or more reflect independent functioning (i.e. functioning without human assistance) without difficulties, scores of 5.57 to 8.88 indicate independent functioning with difficulties, and scores of 5.56 or lower indicate dependent functioning or inability to accomplish (see Table SI).²¹ Cut-off scores similar to earlier studies were used, after correction for transformed score ranges.^{13,20} The LIFE-H covers the ICF domains of participation well, is a valid instrument to measure performance of participation, and has good interrater and intrarater reliability.^{19,22}

Characteristics of CP

Type of motor impairment was recorded as spastic (limb distribution: unilateral/bilateral), dyskinetic, ataxic, or mixed CP.²³ Level of motor functioning was recorded using the GMFCS, addressing five categories of gross motor function ranging from level I (highest level) to level V (lowest level); this has been validated for children and adults with CP.²⁴

Statistical analysis

Descriptive statistics for baseline CP characteristics were performed using SPSS 22 (IBM Corp., Armonk, NY, USA). Mean domain scores and proportions of participants experiencing difficulty (score <8.89) and in need of human assistance (score ≤5.56) were described for observations in four age intervals (16–18y, 19–22y, 23–26y, and 27–34y).

The longitudinal course of difficulty in participation for each LIFE-H domain was analysed using multilevel modelling in MLwiN 2.28 (Centre for Multilevel Modelling, Bristol University, Bristol, UK), in which assessments were clustered within individuals. Age (continuous variable, range 16–34y) and GMFCS level at baseline (categorical variable, GMFCS level I as reference category) were included as independent variables. Additionally, age squared and the interactions of GMFCS level and age (and age squared, if applicable) were included in the model, if significant according to the Wald statistic. To account for individual variation, a random intercept and regression coefficient for age were included if they improved the model, evaluated by the likelihood ratio test. To check the analyses, models were repeated excluding individuals with only a single observation. To study possible decline of participation of individuals in their mid- and late 20s, additional analyses were done by repeating the multilevel models on the subgroup of observations across the age range of 23 to 34 years. A *p*-value lower than 0.05 was considered significant for all analyses.

To study potential influence of dropouts the distribution of sex, GMFCS level, and type of CP of individuals who dropped out (*n*=60) were compared to baseline (*n*=211) using a χ^2 test.

RESULTS

Participant characteristics

The analyses included 379 observations of 151 individuals with CP without intellectual disability over the age range of 16 to 34 years. Most of the participants were male (63%), and most (71%) were classified in GMFCS level I (*n*=107), 11% in GMFCS level II (*n*=16), 7% in GMFCS level III (*n*=11), and 11% in GMFCS level IV (*n*=17). The most common CP subtype was spastic CP (88%; 49% unilateral and 51% bilateral). Others had a dyskinetic (3%), ataxic (3%), or mixed type of CP (6%). Analysis showed that dropout was not selective regarding sex, GMFCS level, or type of CP. The additional analyses over age range 23 to 34 years were conducted on a subsample including 129 observations of 102 individuals. The

distribution of sex, CP subtype, and GMFCS level of this subsample was comparable to the full sample.

Descriptives of participation

Figure 1 presents the mean participation domain scores of the four age intervals for each GMFCS level (I–IV). Figure 2 presents the proportions of individuals experiencing difficulty or needing human assistance in these age intervals by GMFCS level (for details see Table SII, online supporting information). Table SIII (online supporting information) shows the proportions of individuals that considered each LIFE-H item applicable in the four age intervals; for most items, these proportions tended to increase with observations of increasing age intervals.

On average, individuals in GMFCS level I experienced no difficulty in participation in all domains (i.e. mean scores ≥8.89; Fig. 1). Nevertheless, 41% of individuals in GMFCS level I, 77% in GMFCS level II, 88% in GMFCS level III, and 95% in GMFCS level IV experienced difficulty in one or more of the participation domains. The highest proportions of difficulty were observed in individuals in GMFCS level IV, the oldest age range (23–34y), and in the housing, education and employment, and recreation domains (Fig. 2).

Regarding dependency, Figure 1 shows that, on average, individuals with CP functioned independently in all domains (mean scores >5.56), except for adolescents (16–18y) in GMFCS level IV in recreation and community life. Apart from adolescents in GMFCS level IV, small proportions of individuals in GMFCS level II and III reported dependency in the participation domains (Fig. 2).

Long-term course of participation

Table I shows the regression coefficients of the longitudinal models of the six participation domains over the entire age range (16–34y). Random intercepts were included in all models. Random regression coefficients for age were included in the models of interpersonal relationships, recreation, and community life. Table II shows the results of the additional analyses on participation domains of those individuals aged 23 to 34 years. Random intercepts were included in these additional models of housing, education and employment, and responsibilities, and no random regression coefficients for age were included. A ceiling effect was present in the participation scores on all domains; however, residuals of the models were normally distributed, allowing linear modelling.

Regression coefficients for age (and age squared) showed a decrease of housing and interpersonal relationships scores over age range 16 to 34 years (Table I), indicating an increase of difficulty in participation on these domains. Additionally, a decrease of recreation scores was observed over age range 23 to 34 years (Table II). Regression coefficients for GMFCS showed that individuals in GMFCS level IV scored lower (i.e. more difficulty) than individuals in GMFCS level I on all domains (Table I), except for education and employment of individuals in their mid- and

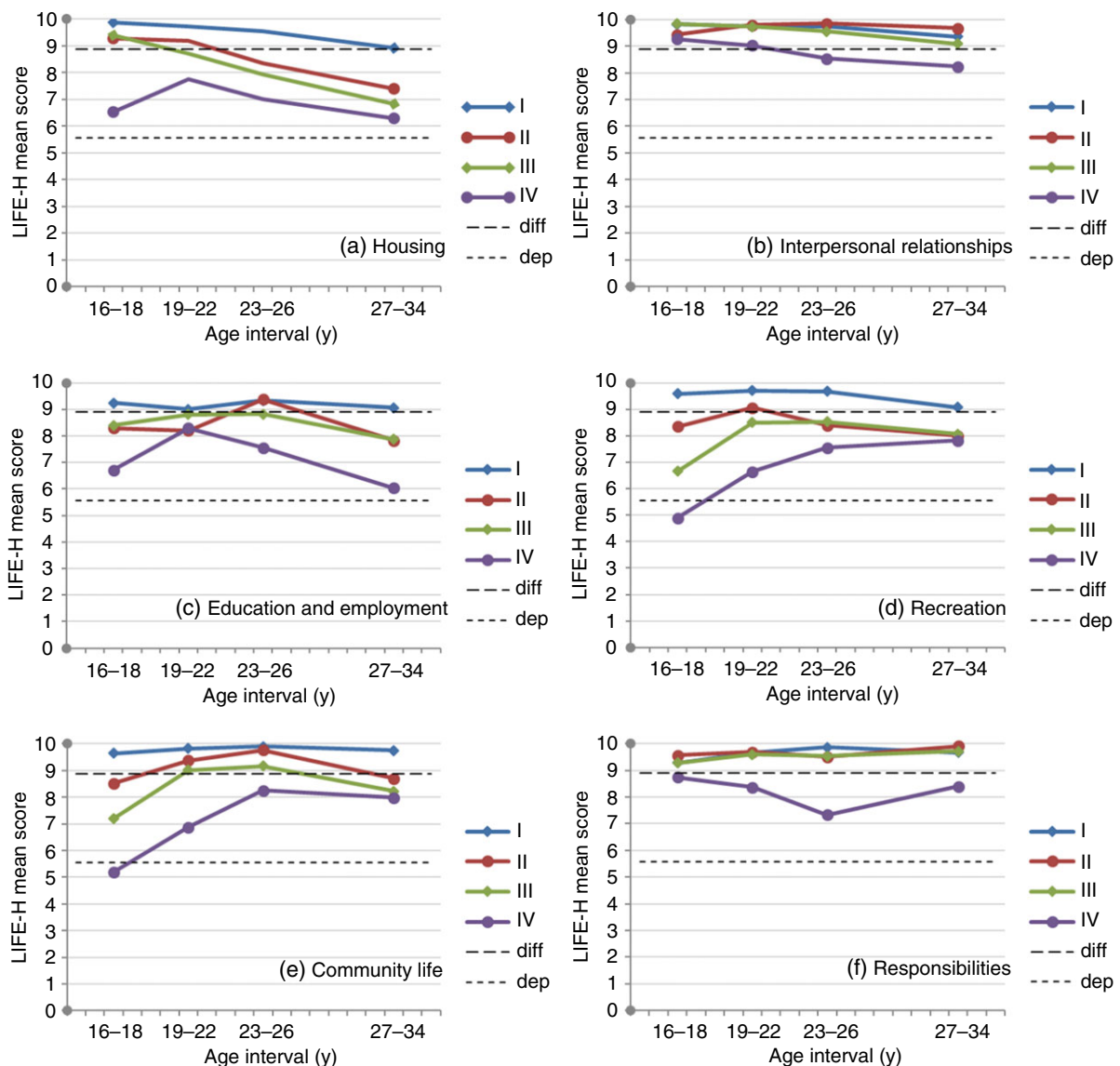


Figure 1: Mean domain scores by Gross Motor Function Classification System (GMFCS) level and age intervals. Number of observations at subsequent age intervals for GMFCS level I: 73 (16–18y), 112 (19–22y), 49 (23–36y), 41 (27–34y); GMFCS level II: 10, 14, 9, 4; GMFCS level III: 8, 7, 6, 4; GMFCS level IV: 11, 15, 8, 8. Dashed line (diff) represents criterion on independent functioning without difficulty (score ≥ 8.89), while dotted line (dep) at score 5.56 represents criterion of dependent functioning (score < 5.56). LIFE-H, Assessment of Life Habits questionnaire 3.0 general short form.

late 20s (Table II). Individuals in GMFCS level II scored lower than those in GMFCS level I for education and employment, and community life, and those in GMFCS level III for recreation and community life (Table I). The course of difficulty in each participation domain is described in more detail below.

Participation in housing

Housing scores decreased with increasing age for all GMFCS levels ($p < 0.001$; Table I). This decrease was stronger for individuals in GMFCS levels II and III compared to GMFCS level I, indicated by the significant interaction of age and GMFCS level II ($p = 0.007$) and

GMFCS level III ($p = 0.002$). The additional analysis confirmed a significant decrease in housing scores with increasing age in the mid- and late 20s ($p < 0.001$; Table II).

Participation in interpersonal relationships

Interpersonal relationships scores showed a quadratic association with age over the 16 to 34 years age range (Table I), indicating a decrease in score irrespective of GMFCS level which was more pronounced towards the end of the age range. The additional analysis confirmed a decrease of interpersonal relationships scores in the mid- and late 20s (Table II).

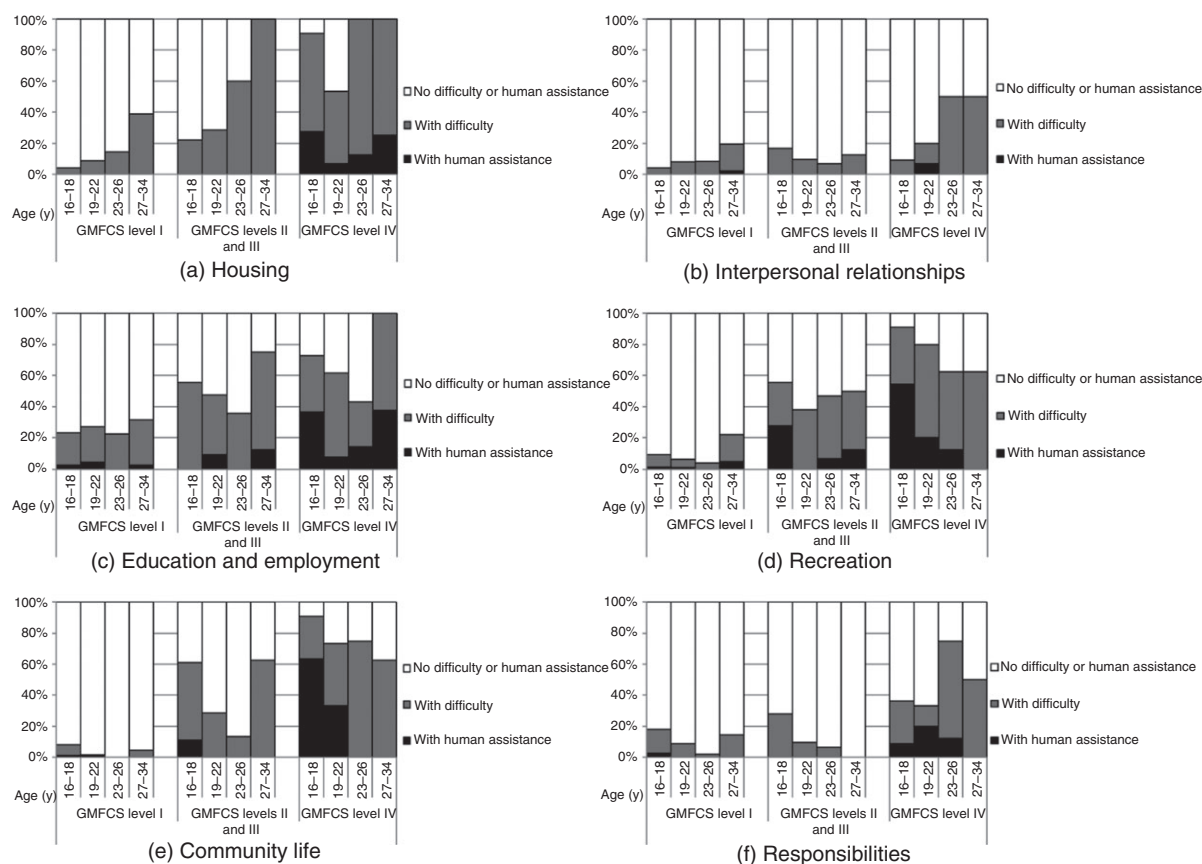


Figure 2: Proportions of individuals with difficulty or needing human assistance by Gross Motor Function Classification System (GMFCS) level and age intervals. Number of observations at subsequent age intervals for GMFCS level I: 73 (16–18y), 112 (19–22y), 49 (23–36y), 41 (27–34y); GMFCS levels II and III: 18, 21, 15, 8; GMFCS level IV: 11, 15, 8, 8.

Participation in education and employment

Education and employment scores showed no significant relationship with age in the 16 to 34 years age range (Table I). Additional analysis showed a trend towards decreasing scores for those in GMFCS level I with increasing age in the mid- and late 20s. Furthermore, significant interactions between age and GMFCS level indicate a stronger decrease of scores for GMFCS level II ($p=0.012$) and GMFCS level IV ($p=0.005$) compared to GMFCS level I in participants in their mid- and late 20s (Table II).

Participation in recreation

Recreation scores showed a different course for GMFCS levels III and IV compared to the relatively stable course of GMFCS level I, indicated by the significant interactions of age and age squared with GMFCS level (Table I). Figure 1 shows an initial increase of scores for GMFCS levels III and IV for age range 16 to 23 years. Additional analysis showed a decrease of scores in the mid- and late 20s, irrespective of GMFCS level ($p=0.008$; Table II).

Participation in community life

Community life scores showed a different course for GMFCS levels II to IV compared to GMFCS level I

(significant interactions of age and age squared with GMFCS level; Table I). An increase of scores for GMFCS levels II to IV is visible for the age range 16 to 23 years (Fig. 1). Additional analysis showed a trend towards decreasing scores in the mid- and late 20s of individuals in GMFCS level I with age and a significant interaction of age and GMFCS, indicating a stronger decrease in GMFCS level II compared to GMFCS level I (Table II).

Participation in responsibilities

For responsibilities, scores showed no significant relationship with age in the 16 to 34 years age range. Additional analysis showed a different course (i.e. a larger increase) in the mid- and late 20s of GMFCS level IV compared to GMFCS level I ($p<0.001$; Table II).

DISCUSSION

This is the first study to present the long-term course of difficulty in participation of individuals with CP without intellectual disability from adolescence into their late 20s and early 30s, described by GMFCS level (I–IV). In their mid- and late 20s, these individuals showed increasing difficulty in five of the six participation domains. Individuals

Table 1: Model regression coefficients of longitudinal course of six participation domains by Gross Motor Function Classification System (GMFCS) level

Associated factors	Housing			Interpersonal relationships			Education and employment			Recreation			Community life			Responsibilities		
	Regression coefficient (95% CI)	p	Wald	Regression coefficient (95% CI)	p	Wald	Regression coefficient (95% CI)	p	Wald	Regression coefficient (95% CI)	p	Wald	Regression coefficient (95% CI)	p	Wald	Regression coefficient (95% CI)	p	Wald
Constant	11.25 (10.78; 11.72)			8.39 (6.94; 9.84)			9.57 (8.85; 10.30)			7.46 (4.34; 10.58)			8.02 (5.35; 10.69)			9.55 (9.10; 10.00)		
Age	-0.08 (-0.10; -0.05)	<0.001	0.14 (0.02; 0.26)	0.026			-0.02 (-0.05; 0.01)	0.203		0.22 (-0.04; 0.48)	0.097		0.15 (-0.07; 0.37)	0.187		0.00 (-0.02; 0.0)	0.975	
Age squared	na			-0.004 (-0.007; -0.002)	0.001		na			-0.005 (-0.011; 0.000)	0.046		-0.003 (-0.007; 0.001)	0.187		na		
GMFCS level I	Reference category			Reference category			Reference category			Reference category			Reference category			Reference category		
GMFCS level II	0.94 (-0.38; 2.25)	0.164		-0.03 (-0.34; 0.28)	0.850		-0.64 (-1.19; -0.10)	0.021		0.46 (-7.68; 8.61)	0.913		-9.09 (-15.80; -2.39)	0.008		0.09 (-0.41; 0.58)	0.731	
GMFCS level III	1.26 (-0.34; 2.86)	0.123		-0.07 (-0.45; 0.30)	0.705		-0.62 (-1.28; 0.05)	0.068		-16.24 (-26.48; -6.00)	0.002		-15.84 (-24.43; -7.25)	<0.001		-0.12 (-0.71; 0.47)	0.695	
GMFCS level IV	-3.41 (-4.65; -2.17)	<0.001		-0.72 (-1.02; -0.42)	<0.001		-1.89 (-2.43; -1.36)	<0.001		-14.83 (-23.48; -6.18)	0.001		-16.25 (-23.91; -8.60)	<0.001		-1.50 (-1.98; -1.01)	<0.001	
Age*GMFCS level I	Reference category			na			na			Reference category			Reference category			na		
Age*GMFCS level II	-0.08 (-0.14; -0.02)	0.007		na			na			-0.10 (-0.80; 0.60)	0.780		0.74 (0.17; 1.31)	0.011		na		
Age*GMFCS level III	-0.11 (-0.18; -0.04)	0.002		na			na			1.13 (0.29; 1.97)	0.009		1.15 (0.45; 1.85)	0.001		na		
Age*GMFCS level IV	0.04 (-0.01; 0.09)	0.147		na			na			0.82 (0.11; 1.54)	0.024		0.98 (0.35; 1.61)	0.002		na		
Age squared*	na			na			na			Reference category			Reference category			na		
GMFCS level I	na			na			na			0.002 (-0.013; 0.016)	0.836		-0.015 (-0.027; -0.004)	0.011		na		
GMFCS level II	na			na			na			-0.021 (-0.038; -0.003)	0.018		-0.022 (-0.035; -0.008)	0.002		na		
GMFCS level III	na			na			na			-0.012 (-0.027; 0.002)	0.093		-0.016 (-0.029; -0.004)	0.011		na		
GMFCS level IV	na			na			na											

Bold indicates significant regression coefficient according to the Wald statistic ($p < 0.05$). CI, confidence interval; na, not applicable – variable did not meet criteria for inclusion (was not significant according to the Wald statistic [$p < 0.05$]); SE, standard error of the model regression coefficient.

Table II: Additional models over 23y of age: model regression coefficients of longitudinal course of six participation domains by Gross Motor Function Classification System (GMFCS) level

Associated factors	Housing			Interpersonal relationships			Education and employment			Recreation			Community life			Responsibilities		
	Regression coefficient (95% CI)	p Wald	Regression coefficient (95% CI)	Regression coefficient (95% CI)	p Wald	Regression coefficient (95% CI)	Regression coefficient (95% CI)	p Wald	Regression coefficient (95% CI)	Regression coefficient (95% CI)	p Wald	Regression coefficient (95% CI)	Regression coefficient (95% CI)	p Wald	Regression coefficient (95% CI)	p Wald		
Constant	12.08 (10.87; 13.30)		11.22 (9.75; 12.69)	10.60 (8.99; 12.21)		11.37 (9.90; 12.84)	10.54 (9.74; 11.34)		11.37 (9.90; 12.84)	10.20 (9.40; 11.00)		11.37 (9.90; 12.84)	10.54 (9.74; 11.34)		10.20 (9.40; 11.00)			
Age	-0.11 (-0.15; -0.07)	<0.001	-0.06 (-0.10; -0.02)	-0.05 (-0.11; 0.01)	0.003	-0.07 (-0.12; -0.02)	-0.03 (-0.055; 0.003)	0.008	-0.07 (-0.12; -0.02)	-0.02 (-0.05; 0.01)	0.081	-0.07 (-0.12; -0.02)	-0.03 (-0.055; 0.003)	0.008	-0.02 (-0.05; 0.01)	0.27		
GMFCS level I	Reference category		Reference category	Reference category		Reference category	Reference category		Reference category	Reference category		Reference category	Reference category		Reference category			
GMFCS level II	-1.25 (-1.83; -0.68)	<0.001	0.20 (-0.31; 0.71)	5.48 (0.91; 10.05)	0.437	-1.16 (-1.83; -0.50)	2.72 (0.28; 5.17)	0.001	-1.16 (-1.83; -0.50)	-0.55 (-2.77; 1.67)	0.029	-1.16 (-1.83; -0.50)	2.72 (0.28; 5.17)	0.001	-0.55 (-2.77; 1.67)	0.627		
GMFCS level III	-1.83 (-2.47; -1.19)	<0.001	-0.22 (-0.79; 0.35)	-0.92 (-6.01; 4.17)	0.556	-1.08 (-1.82; -0.33)	-0.70 (-1.83; 3.22)	0.005	-1.08 (-1.82; -0.33)	-0.91 (-3.46; 1.63)	0.588	-1.08 (-1.82; -0.33)	-0.70 (-1.83; 3.22)	0.005	-0.91 (-3.46; 1.63)	0.482		
GMFCS level IV	-2.58 (-3.11; -2.06)	<0.001	-1.16 (-1.63; -0.70)	3.46 (-0.84; 7.75)	0.115	-1.69 (-2.29; -1.08)	-2.17 (-4.19; -0.15)	<0.001	-1.69 (-2.29; -1.08)	-5.80 (-7.91; -3.68)	<0.001	-1.69 (-2.29; -1.08)	-2.17 (-4.19; -0.15)	<0.001	-5.80 (-7.91; -3.68)	<0.001		
Age*GMFCS level I	na		na	Reference category		na	Reference category		na	Reference category		na	Reference category		Reference category			
Age*GMFCS level II	na		na	-0.22 (-0.38; -0.05)	0.012	na	-0.12 (-0.21; -0.03)	0.012	na	-0.12 (-0.21; -0.03)	0.012	na	-0.12 (-0.21; -0.03)	0.012	0.01 (-0.07; 0.09)	0.757		
Age*GMFCS level III	na		na	0.00 (-0.18; 0.18)	0.997	na	-0.06 (-0.16; 0.03)		na	-0.06 (-0.16; 0.03)		na	-0.06 (-0.16; 0.03)		0.03 (-0.07; 0.12)	0.302		
Age*GMFCS level IV	na		na	-0.22 (-0.37; -0.07)	0.005	na	0.02 (-0.06; 0.09)	0.646	na	0.02 (-0.06; 0.09)	0.646	na	0.02 (-0.06; 0.09)	0.646	0.14 (0.06; 0.22)	<0.001		

Bold indicates significant regression coefficient according to the Wald statistic ($p < 0.05$). CI, confidence interval; na, not applicable – variable did not meet criteria for inclusion (was not significant according to the Wald statistic [$p < 0.05$]); SE, standard error of the model regression coefficient.

in GMFCS levels III and IV showed an improvement in participation in recreation and community life during adolescence and early adulthood.

As hypothesized, difficulty in participation increased with increasing age in the mid- and late 20s in all domains (except for responsibilities); this may be due to an age-related change of desired or socially defined roles when developing into full adulthood,¹⁵ such as expectations regarding living situation, employment, and maintaining relationships. This mechanism, when taking on adult roles or increasing expectations of the young adults and their environment lead to more difficulties, can be indicated as 'growing into a deficit'.²⁵ This assumption is supported by an increase in the proportion of the LIFE-H items considered relevant to participants with increasing age (Table SIII). No longitudinal studies were available for comparison. Cross-sectional studies in adult populations, however, found no significant relationship between difficulty in participation and age.^{5,14} Still, Boucher et al. also argued younger participants seemed to participate without difficulty more often.⁵ The discrepancy with the present results might be attributed to the specific age window and/or larger sample size of the study, therefore focusing more specifically on the phase of development towards adult roles, when demands and expectations are assumed to change. Future research may investigate this assumption by studying the possible discrepancy between expectations for adult life of individuals with CP and their actual participation performance. For now, our results indicate that attention is required for participation difficulties of individuals with CP in their 20s.

Our results add to the evidence that individuals with CP who are more severely physically impaired experience more problems in participation compared to those with milder impairment.^{5,9,10} Furthermore, in recreation and community life, individuals with lower levels of motor functioning continued to develop their level of participation into their early 20s, while those with higher levels of motor functioning reached maximal levels at a younger age. As a consequence, individuals in GMFCS level IV reached independence in participation at an older age. In contrast, these individuals have been found to reach their motor capacity limits younger than less affected peers, or even decline in motor capacity in their adolescence.²⁶ Furthermore, according to their level of motor functioning, they require human assistance in specific movements, for example in making transfers.²⁴ The present results indicate that prerequisites of participation differ from those of motor functioning or capacity. Therefore, although level of GMFCS is an important determinant for participation, there are also other factors to consider. Assistive devices or adaptations, for instance, may successfully contribute to independent participation of individuals in GMFCS level IV.

We found high average levels of participation; however, substantial proportions of individuals with CP experienced difficulty and some needed human assistance in participation. Domestic life, education and employment, and

recreation deserve special attention, since the proportions of difficulty were particularly high in these domains.^{6,14} The discrepancy between high average levels of participation versus large proportions of individuals with CP experiencing difficulty indicates a need to systematically check for participation difficulties in order to offer appropriate personalized care.

Strengths and limitations

Because of the exclusion of individuals with intellectual disability and the dropouts during follow-up, this study included low numbers of participants in GMFCS levels II to IV (especially in the oldest age interval) which increases uncertainty. The additional analyses over the 23 to 34 years age range lacked the added value of longitudinal research, since most observations in this age range were from the 13-year follow-up only and were, therefore, of a cross-sectional nature. Furthermore, the LIFE-H domain scores were averaged from six to eight ordinal items. These scores were assumed to be at the interval level, which was previously supported by their unidimensionality.²⁰

We are aware of an ongoing discussion regarding the concept of participation, with different approaches to define participation, also including more subjective aspects of participation (such as involvement) and participation-related constructs (such as activity competence).^{27,28} In the present study we used the ICF definition of participation with its qualifiers, assessing performance objectively. Accordingly, the LIFE-H domain scores were designated as participation outcomes. Some of the items may be considered activities rather than participation (e.g. moving around within your home), but most items were classified to assess participation.²⁹ Our results provide valuable insights for individuals with CP and rehabilitation clinicians regarding experienced difficulty in participation. Future studies may add to this regarding subjective aspects of participation, reflecting individuals' preferences or satisfaction with participation.

Clinical implications and recommendations

Clinicians should be aware that increasing proportions of individuals with CP in their 20s and early 30s may experience difficulties in participation, particularly in domestic life, education and employment, and recreation. These individuals may benefit from systematic screening of potential participation problems and adequate support or training in several life areas, for example supporting them towards independent living or when entering the labour market.³⁰ Our results address difficulty in participation performance. Other aspects of participation, such as frequency of participation or an individual's subjective experience of participation, are also important to consider in clinical decision-making. Specific consideration is needed for individuals in GMFCS level IV in order to set realistic expectations for future functioning, since they continuously experienced more difficulties than their peers in adolescence and adulthood. Future studies might extend the present results by investigating the subgroup of individuals

with CP *with* intellectual disability, since intellectual disability is an important factor limiting participation,^{8,9} and by estimating the influence of personal and environmental factors on difficulty in participation.

CONCLUSION

Difficulty in participation increases in the mid- and late 20s of individuals with CP without intellectual disability. Although individuals with CP have high mean levels of participation, many still experience difficulty in participation. Thus, systematic screening and timely support seem necessary to improve the development of optimal participation of young adults with CP.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: Inclusion of study participants.

Figure S2: Number of observations at each measurement by age group.

Table SI: Scoring Life Habits Accomplishment scale

Table SII: Scores on the LIFE-H for each participation domain per age interval and GMFCS level

Table SIII: Proportion of observations where items of LIFE-H were applicable

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RESUMEN

PATRÓN DE DIFICULTAD A LARGO PLAZO EN LA PARTICIPACIÓN DE INDIVIDUOS CON PARÁLISIS CEREBRAL DE 16 A 34 AÑOS: UN ESTUDIO PROSPECTIVO DE COHORTE

OBJETIVO Determinar el curso de dificultad a largo plazo en la participación de personas con parálisis cerebral (PC) sin discapacidad intelectual entre los 16 y los 34 años de edad.

MÉTODO Se incluyeron 151 con PC de 16 años a 20 años (63% hombres, 37% mujeres, sistema de clasificación de la función motora gruesa [GMFCS] niveles I-IV, sin discapacidad intelectual). El cuestionario corto *Evaluación general de hábitos de vida 3.0* (Assessment of Life Habits questionnaire 3.0 general short form) se usó hasta tres veces cada dos años y a los 13 años de seguimiento (13 años de seguimiento: $n = 98$). Los puntajes (rango 0-10) reflejan dificultad y asistencia en la participación en vivienda, educación y empleo, relaciones interpersonales, recreación, vida comunitaria y responsabilidades. Se utilizaron modelos multinivel para determinar el curso de dificultad en la participación según el nivel de GMFCS.

RESULTADOS A pesar de los altos niveles de participación promedio, del 41 al 95% de los adolescentes y adultos jóvenes con PC experimentaron dificultades. La dificultad en la participación en la vivienda y las relaciones interpersonales aumentó desde la edad de 16 años en adelante, y en la mayoría de las otras áreas de la vida a mediados y finales de los 20 años. En adolescentes en los niveles III y IV de GMFCS, la participación en la recreación y la vida comunitaria mejoró hasta los 23 años.

INTERPRETACIÓN Las personas con PC experimentan dificultades crecientes en la participación a mediados y finales de los 20 años. Los profesionales de la salud deben verificar sistemáticamente las dificultades de participación en adultos jóvenes con PC y ofrecer a tiempo un tratamiento personalizado.

RESUMO

CURSO EM LONGO PRAZO DAS DIFICULDADES DE PARTICIPAÇÃO EM INDIVÍDUOS COM PARALISIA CEREBRAL DE 16 A 34 ANOS DE IDADE: UM ESTUDO DE COORTE PROSPECTIVO

OBJETIVO Determinar o curso em longo prazo das dificuldades de participação em indivíduos com paralisia cerebral (PC) sem deficiência intelectual entre 16 e 34 anos de idade.

MÉTODO Cento e cinquenta indivíduos com PC e idades entre 16 e 20 anos foram incluídos (63% do sexo masculino, 37% do sexo feminino; níveis do Sistema de Classificação da Função Motora Grossa [GMFCS] I-IV; sem deficiência intelectual. A Questionário de Avaliação dos Hábitos de Vida 3.0 formulário curto geral (Assessment of Life Habits questionnaire 3.0 general short form) foi usada até três vezes bianualmente em um acompanhamento de 13 anos (acompanhamento de 13 anos: $n=98$). Os escores (variando de 0–10) refletem dificuldade e assistência na participação em casa, educação e emprego, relações interpessoais, recreação, vida na comunidade e responsabilidades. Modelos multiníveis foram usados para determinar o curso das dificuldades de participação por nível GMFCS.

RESULTADOS Apesar da alta média de níveis de participação, 41 a 95 por cento dos adolescentes e adultos jovens com PC vivenciaram dificuldades. Dificuldades na participação em casa e nas relações interpessoais aumentaram da idade de 16 anos em diante, e na maior parte das áreas da vida entre a metade o fim da terceira década de vida. Em adolescentes de níveis GMFCS III e IV, a participação em recreação e vida em comunidade melhorou até a idade de 23 anos.

INTERPRETAÇÃO Indivíduos com PC vivenciam crescentes dificuldades na participação entre a metade e o fim da terceira década de vida. Clínicos devem sistematicamente checar dificuldades de participação em adultos jovens com PC, para oferecer tratamento personalizado oportunamente.